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# Health literacy: a necessity for increasing participation in health care

Current UK government policy places much emphasis on increasing patient participation in health care, stressing that access to better information is required to support patients' participation and to enable them to make choices in their own health care.<sup>1</sup> Patient participation has great practical value in achieving better health outcomes among those who actively participate in healthcare decisions compared to those who do not.<sup>2</sup> Previous studies have shown that patients are not currently involved to the degree that they would prefer,<sup>3</sup> and that this desire for engagement is consistent regardless of social background and educational status.<sup>4</sup>

Those who currently participate in healthcare decision making tend to be younger, female, educated, articulate patients of higher socioeconomic status.<sup>5</sup> While the range of methods for patient communication in clinical settings has grown, most are dependent on higher levels of literacy and numeracy. There is relatively little published evidence concerning attempts to encourage people from lower literacy backgrounds to make informed health decisions through the use of different types of decision support materials or approaches.<sup>6,7</sup>

Differences in literacy and numeric skills lead to marked variation in an individual's ability to obtain relevant health information, and in their opportunity and capability to apply that information in interactions with health professionals and services.<sup>8</sup> It

follows that without careful implementation, current government policies may inadvertently exacerbate existing inequalities in health by favouring those already advantaged as a consequence of their education and basic skills.<sup>9</sup> It is possible that this is one of the reasons why, despite an overall increase in health in the UK population, the 'inequalities gap' between the most and least advantaged in society is widening.<sup>10</sup>

## POOR HEALTH LITERACY AS A BARRIER TO PARTICIPATION IN HEALTH CARE

Functional literacy (the ability to read simple text and write simple sentences about everyday life), is a basic skill enabling people to participate more fully in society. There is consistent evidence indicating a link between low literacy and poorer health outcomes. People with lower literacy levels are generally 1.5 to 3 times more likely to have poor health outcomes than people with higher literacy levels.<sup>8</sup> The prevalence of low literacy in England is surprisingly high.

The most recent (2003) English national survey of literacy, numeracy, and use of information technology, also known as the The Skills for Life survey, assessed the extent to which these basic skills were present at a level needed to achieve full potential (Level 2 in the National Qualification Framework). This is described as 'being able to understand a range of

texts of varying complexity accurately and independently, and to extract information of varying length and detail from different sources'.<sup>11</sup> This survey of 8000 people of working age was based on a direct measurement of skills (for example, on being shown a poster for a concert, questions were asked such as 'where is the concert, how much will it cost for two people to attend?'). The results were divided into levels which were based on the English national curriculum and showed that 56% (literacy), and 75% (numeracy) of those surveyed have skills below those needed to achieve their full potential, while the opportunities offered by modern information technology, such as the internet, are only fully used by a very small percentage of the population (9%).<sup>11</sup>

Such results provide practical challenges in health communication. The majority of printed information leaflets used in health care already have a reading age higher than the average population.<sup>12,13</sup> Interventions to promote participation, shared decision making, and informed consent may only therefore reach a proportion of the population.

Low literacy and numeracy may contribute to inequity of access to the benefits of prescription medication. It is known that people with low literacy skills are more likely to make mistakes in interpreting medication instructions and warning labels.<sup>14</sup> This increases the risk of both unintentional sub-optimal compliance

with medication regimes, and increases the risk of adverse events. In addition, the drive to more cost-effective generic prescribing may differentially affect those with low basic skills; community pharmacists report that patients with low literacy experience difficulties when different brands of the same medication are issued.<sup>15</sup>

Current NHS initiatives to increase patient choice may also be less accessible for people with low literacy. Under the NHS Choose and Book system, patients requiring specialist care are offered a range of potential services; they then choose their preferred service and book their clinic appointment. It can be hypothesised that this process will be more difficult for people with low literacy skills, although to date no research has been undertaken to investigate this; however, research suggests that Choose and Book fails to deliver the expected choice to patients.<sup>16</sup>

The relationship between literacy and the quality and outcome of healthcare interactions has been the subject of increasing attention, especially in the US where the study of 'health literacy' has developed over the past decade.<sup>17</sup> Health literacy has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health.<sup>17</sup> Basic literacy and numeracy skills are fundamental requirements for health literacy, but are not sufficient. A person can be 'literate' within a familiar environment and context, but functionally 'illiterate' when required to comprehend and respond to unfamiliar vocabulary and concepts in an unfamiliar environment. For many individuals — as patients, carers, and members of the community — healthcare settings are unfamiliar environments in which many are exposed to unfamiliar vocabulary and concepts. To make the healthcare 'environment' less alienating, it is important that healthcare providers, and those responsible for patient management and administration are sensitised to the challenges faced by patients in communicating effectively. Simple practical steps that could be taken by health professionals are to assess the

readability of the printed materials that they are using and to make conscious efforts to minimise the use of technical language, using lay terminology whenever possible.

Not surprisingly, research on health literacy over the past decade has shown that those who have poor health literacy are less responsive to health education and use of disease prevention services, less able to manage successfully chronic disorders, such as diabetes and asthma, and incur higher healthcare costs.<sup>8,18</sup> This research has led to progressive testing of interventions designed to mitigate the effects of poor health literacy through modified communications, and improved service organisation.<sup>19</sup> For these reasons, understanding the concept of health literacy, and the research that underpins the concept are especially important in achieving current UK priorities to promote greater patient participation in health care and to achieve greater equity in health outcomes.

Perhaps more challenging still, Kickbusch *et al* have argued that health literacy is 'a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility'.<sup>20</sup> Healthcare professionals and patients have vastly different status and roles in healthcare interactions. In addition to improving health literacy, there is a need for a more symmetrical balance of 'power' to encourage relationships that actively foster joint decision making and, therefore, facilitate genuine participation in decision making.

Disappointingly, there has been little research into health literacy in the UK. The National Consumer Council (now referred to as 'Consumer Focus') reported that low health literacy appears to be particularly prevalent among lower socioeconomic groups, ethnic minorities, older people, and those with chronic conditions or disabilities.<sup>21</sup> This reduced ability to access information and function effectively in the current health service may be an explanatory factor in health inequalities.<sup>22</sup> Reviewing the evidence, the American Medical Association found that health literacy is a stronger predictor of health status than age, income, employment status, education level, race, or ethnic

group.<sup>23</sup> Without careful implementation, current policies to promote greater patient participation in healthcare decisions may exacerbate existing inequities by engaging only those who are most literate and confident in a healthcare setting, and further alienating those least able to navigate their way into the healthcare system, interact successfully with healthcare professionals, and understand disease prevention and management options.

## WHAT INTERVENTIONS WORK?

Although more research is needed to determine the nature of the situation in the UK, the data from the 2003 national literacy survey (Skills for Life) provide a good indication of the likely scale of the problem and its impact on health care in the UK. Low health literacy is a real and significant barrier to patient participation in health care in England.

Individuals with undeveloped skills in reading, oral communication, and numeracy not only have less exposure to health and medical information, but also less developed skills to act upon the information received. For these reasons, strategies to promote health literacy will remain inextricably tied to more general strategies to promote literacy, numeracy, and language skills in populations. A recent review of more complex interventions aimed at improving health outcomes for people with limited literacy identified only 15 trials; of which only one was conducted on a UK population.<sup>24</sup> The interventions studied were mostly focused on health education and management for patients, only two interventions were directed at health professionals and only one encompassed both. Very few focused on clinical outcomes. These findings are in line with an earlier systematic review conducted in the US.<sup>26</sup> More comprehensive interventions, aimed both at improving patient knowledge and empowerment as well as better sensitisation of service providers to the difficulties experienced by individuals with low literacy are considered to be more effective.<sup>19</sup>

As a basic first step, health professionals should consider the health literacy of their patients while exploring their 'ideas,

concerns, and expectations'.<sup>26</sup> There is evidence that once low health literacy is considered, healthcare professionals do try to modify their communication, but checking understanding using the 'teach back' technique (asking patients to repeat back information and instructions) and use of visual models are more effective and less commonly used techniques.<sup>27</sup> It would be helpful to heighten awareness of the importance of patient literacy and numeracy skills during medical undergraduate and specialist training, so that all doctors are equipped with the skills they need to support patients.

For researchers to develop a broader understanding, the wider use of simple, standardised assessments of patient health literacy in clinical situations should be encouraged. Simple assessment tools already exist and are increasingly used in the US. They include the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). Both these instruments have been developed in the US, although recent trials have tested them in UK populations.<sup>28</sup>

Outside of the healthcare system, there are initiatives that aim to combine the strengths of lifelong learning, with a focus on health and making decisions about health, such as the English 'Skilled for Health' programme.<sup>29</sup> It brings health 'content' into an adult basic skills programme utilising 'empowering' adult learning methods that are intended to equip learners with skills and confidence compatible with the approach to health literacy advocated by Kickbusch.<sup>20</sup>

## CONCLUSION

Current understanding of the relationship between literacy and health, and growing understanding of the concept of health literacy should temper uncritical enthusiasm for current policy to increase patient participation in health care. Unless health literacy is better understood and more overtly accounted for in the implementation strategy, the policy goal to achieve an actively participating patient population is unlikely to be met, reaching only a subset of patients with higher literacy skills and greater confidence with the healthcare system. Worse, increasing

patient participation, without specific interventions to address low health literacy, may well result in increased health inequalities.

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## Provenance

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